Research Report

The Economic and Social Council

Privacy and non-discrimination with regards to genetic information

MUNISH

Forum	ECOSOC
Issue:	Privacy and non-discrimination with regards to genetic information
Student Officer:	Xiaman Wu
Position:	President

Introduction

In our modern-day society, technology has transformed the way we view our body and health, surpassing natural boundaries and perceived limits. Technology currently enables us to predict our future health through looking at genetics and family history, being able to identify hereditary genetic diseases and the probability they will transcend generations. The obvious advantage of such tests is their insight on our future; however, they can also hugely affect our present. Such genetic tests are by no means considered private information, as they must be present in an individual's medical records. Many institutions associated to an individual have the right to review an individual's medical records, and therefore able to know the potential future diseases of an individual. As a consequence, such genetic testing can be used against an individual in the present, despite being completely healthy. Employers are often more reluctant to hire employees with higher risk of hereditary diseases, whilst health insurance companies are unwilling to take on a client with a risky future. Therefore, it is clear that international legislation allows little privacy for an individual's genetic information, and offers little to prevent such records from being used against individuals.

Definition of Key Terms

Genetic Information

Genetic information describes *'the genetic potential of an organism carried in the base sequence of its DNA (or, in some viruses, RNA) according to the genetic code.' (Oxford Dictionaries)* Genetic information includes hereditary conditions, traits and biological information, therefore able to predict likely potential hereditary diseases. Such information is obtained through testing, and usually only upon request by the individual, often at a relatively high cost. When referring to third parties obtaining genetic information, this includes the results of genetic tests, as well as tests from family members, including identification of hereditary diseases and disorders that family members possess, often extended to family medical history. Such information also includes records of all requests for genetic tests and all performed tests, as well as any participation in trials or medication prescribed.

Genetic Discrimination

Genetic discrimination refers to when genetic information is used as a premise to treat individuals differently. This is usually done by employers or health insurance companies, as specific genetic predispositions increases the risk of hereditary diseases, making the individual less favorable as a worker and more risky as a health insurance client.

General Overview

The science of genetics has become increasingly accessible, therefore making genetic tests increasingly common. Such tests are designed to identify genetic diseases and disorders that may be hereditary in a family. The most common reasons for genetic tests are:

- *‘Identifying unaffected individuals who carry one copy of a gene for a disease that requires two copies for the disease to be expressed, for example Huntington's disorder*
- *Preimplantation genetic diagnosis*
- *Prenatal diagnostic testing*
- *Newborn screening*
- *Genealogical DNA test (for genetic genealogy purposes)*
- *Presymptomatic testing for predicting adult-onset disorders such as Huntington's disease*
- *Presymptomatic testing for estimating the risk of developing adult-onset cancers and Alzheimer's disease*
- *Confirmational diagnosis of a symptomatic individual*
- *Forensic/identity testing’ (Wikipedia)*

However, the current procedure of genetic testing lends little privacy to the individual regarding test results. Genetic test results remain on an individual’s medical records forever, and associated institutions such as insurance companies and employers often have the right to access these medical records, and thus able to know the individual’s genetic predisposition and any possibility of hereditary diseases.

Brief History of the Science of Genetics

The study of genetics started with Gregor Johann Mendel in 1866, who studied pea plants, developing the concept of Mendelian Inheritance. In 1900, these ideas were revisited by Hugo de Vries, Carl Correns and Erich von Tschermak., applying Mendel's basic principles to more organisms, most famously the fruitfly. This eventually led to the development of the Mendelian model in 1925. At the same time, population genetics was introduced by mathematicians, explaining the process of evolution. The next stage of the science of genetics took the basic patterns established in the early 20th century to investigate DNA specifically, focusing on different types of organisms, such as viruses and bacteria. Consequently, the discovery of DNA structure in 1953 moved the development of genetics into molecular genetics. Since then, techniques have been developed to regulate, and later manipulate gene expression, leading to genetic engineering, where the genetic information of organisms is manipulated to suit demands or environments.

Privacy of Genetic Information

Currently, there is limited privacy for genetic information. Genetic testing is often not only conducted for the interest of the individual, but also for family, future mates, employers, insurers, the government, and sometimes even the press. Often, the intentions of third parties with this genetic information is not aligned, and sometimes directly contradictory, to the individual's welfare. However, because these genetic tests and their results must show on medical records, and many third parties are legally allowed access to these medical results, many third parties are able to access an individual's genetic testing results, even against an individual's consent.The standard 'release of medical information' includes genetic testing results, and thus any institutions that requires any medical history or information can likely access past genetic testing results of the individual in question. Therefore, the privacy regarding genetic information is clearly lacking, especially when considering the potential impact of third parties acquiring this information. However, it is important to note that although this is the norm, different countries have varying policies regarding genetic information privacy.

Discrimination on the Basis of Genetic Information

Currently, many nations, like the USA, have implemented laws officially forbidding discrimination of employees or individuals on the basis of genetic information. However, as will later be evaluated, these techniques are often limited in success. Discrimination based on genetic information is not uncommon in More Economically Developed Countries (MEDCs), as insurance companies often review medical records before deciding on coverage, often denying it to those tested to possess high risk for potential hereditary diseases. Furthermore employers are less willing to hire those with genetic 'defects' as it could affect the employees work potential. Furthermore, even if the individual is currently healthy, they may still be rejected for jobs on the basis of genetic test results as employers are afraid it might increase health insurance premiums for all workers within the firm. Therefore it is clear that the discrimination based on genetic information is interconnected. The discrimination placed by insurance companies reflects not only on an individual's ability to obtain insurance, but also their ability to obtain a job, as employers must also consider the insurance premiums for their workers within the salary package. It is thus clear that genetic information discrimination is a highly prevalent and urgent issue in modern-day society, with strong roots and serious repercussions.

Major Parties Involved and Their Views

United Nations Educational, Scientific and Cultural Organization (UNESCO)

UNESCO is dedicated to pursue goals set by the international community, such as the Millennium Development Goals. It achieves this through 5 programme sectors: *'Education, Natural Sciences, Social and Human Sciences, Culture, Communication and Information' (UNESCO).* The sectors most relevant to this issue are of course 'Natural Sciences' and 'Communication and Information'. Regarding natural sciences, UNESCO strives to *'advance and promote science in the interests of peace, sustainable development and human security and well-being, in close collaboration with its Member States and a wide variety of partners. It is the only United Nations specialized agency, symbolized by the 'S' in the acronym, with a specific mandate for science.' (UNESCO)* Its work in this area includes:

- *'Catalyses international cooperation in science;*
- *Promotes dialogue between scientists and policy makers;*
- *Builds capacity in science;*
- *Advocates for science;*
- *Acts as a platform for sharing ideas and standard setting;*
- *Implements programmes and projects in science throughout the world.' (UNESCO)*

Regarding 'Communication and Information', UNESCO or structured into two components, the first of which is named 'Freedom of Expression and Media Development' and the latter of which is 'Knowledge Societies Division'. The objectives of this segment of UNESCO are:

- *'Promoting the free flow of ideas and universal access to information*

- *Promoting the expression of pluralism and cultural diversity in the media and world information networks*
- *Promoting access for all to ICTs' (UNESCO)*

United States of America

Being a leading nation with regards to genetic scientific research, the USA is simultaneously one of the countries most affected by this problem, and consequently also one of the countries giving most attention to solving the problem. The problem of discrimination based on genetic information is prevalent in USA, where insurance companies have been known to deny coverage to those with higher risks of hereditary diseases, or demand higher premiums. This problem often leaves many victims without health insurance in the USA, or afraid to conduct DNA testing in fear of such consequences. Therefore, the USA has dedicated significant attention to the problem in recent years, implementing numerous legislative measures. However, their effectiveness has been limited, despite best intentions, as the problem is still very much prevalent today.

Timeline of Events

Date	**Description of event**
1866	Study of genetics starts with Gregor Johann Mendel
1925	Mendelian model for genetics developed
1953	Discovery of the double helix structure of DNA
October 12th, 2003	International Declaration on Human Genetic Data
July 21st, 2004	ECOSCO publishes the resolution: 'Genetic privacy and non-discrimination'
May 21st 2008	Genetic Information Nondiscrimination Act enacted (USA)

UN involvement, Relevant Resolutions, Treaties and Events

This issue is yet to receive substantial limelight from the international community, mainly because it is an issue not universally prevalent or urgent, being only an issue in More Economically Developed Countries (MEDCs) who have the resources and technology to conduct genetic tests. Nevertheless, there have been some attempts to tackle the issue:

- International Declaration on Human Genetic Data, 12 October 2003
- Genetic privacy and non-discrimination, 21 July 2004 **(E/RES/2004/9)**

Evaluation of Previous Attempts to Resolve the Issue

Genetic Information Nondiscrimination Act

This act, among many previous ones with similar intentions, was enabled by the United States Congress in 2008, dictating that in the USA, genetic information cannot be used as a factor when making health insurance plans or employment decisions. Therefore, genetic predisposition could no longer be used by insurance companies to deny coverage or demand higher premiums from a healthy individual. Furthermore, employers could not take genetic information into consideration when making hiring, firing or promoting decisions. However, although this act officially makes such decisions illegal, it cannot fully prevent companies or firms from taking genetic information into consideration, and not stating it as the official reasoning, therefore limiting the success of such acts. Furthermore, there are still many areas the law does not tackle, as it *'does not cover life insurance, disability insurance and long-term care insurance.' (National Human Genome Research Institute)*

Alias Genetic Counseling and Testing

This refers to a type of genetic testing that does not reveal the identity of the individual receiving the tests. Probands (those undergoing genetic tests) are identified by codes or alternative identifies as opposed to actual names, and thus there is nothing to connect the proband to the individual directly. All tests and results are stored, retrieved and released on the basis of this new identifier, and thus it is impossible for such information to be obtained by third parties the proband does not wish to release the information. Therefore, such methods of genetic testing have proven to be very successful. However, this option is currently extremely rare globally, and is therefore a privilege most probands cannot acquire. To improve its effectiveness, such measures need to be made more available and efficiently implemented worldwide.

Possible Solutions

As already structured in the General Overview, this issue should and must be approached from different angles. The privacy of genetic tests and genetic information needs to be enhanced and secured, whilst the discrimination based on genetic information must also be eliminated. Both parts go hand in hand, as solving one will aid solving the other.

However, tackling both simultaneously is the most effective way to find long-term solutions to this issue.

Improving privacy of genetic information

- More careful methods of testing, such as alias testing, would help ensure that the individual has complete control over the results of his/her genetic testing from the very beginning. These methods allow the individual to stay anonymous if desired, and thus for their results to remain private to the individual only, preventing abusive use of the results.
- It is important to provide accurate, clear information to probonds before genetic testing. Many often do not realize how their results may not be completely private and may be used against them by third party institutions.
- However, there are also ethical issues involved regarding the extent of privacy with genetic information. The question lies in when it is in order for genetic information to be disclosed to protect third parties. For example, should family members, children in particular, be alerted if their parents/family has been found to possess genes for a specific hereditary disease, even if the probond wants to keep the information private?
- Increased security systems and regulations regarding genetic information should be enforced. Genetic information can not only be used by third party institutions with legal rights to view them, but also third party individuals that may hack or illegally obtain this information for ulterior motives. With the technology available today, much can be achieved through knowing or acquiring DNA information of others. Despite this not being the focus of this issue, it also deserves some attention in the resolutions, as falls under the privacy of genetic information

Improving non-discrimination of genetic information

- How much access to health information should third party associations have?
    - Should employers be able to access the medical reports of their potential employees, and at what stage of the employment process? Perhaps they should only have access after they have hired an employee, or perhaps they should only be able to view limited sections of the report, parts only directly relevant to the position.
    - Should health insurance firms be able to view complete medical histories and reports of all potential clients, especially before they have made any decision to give insurance to these clients? Do they have the right to view these medical histories

considering they must know what risks they are signing on to when providing health insurance?

- Should sanctions or incentives be put in place to discourage third parties from viewing individual medical reports and using them against the individual? For example, subsidies could be given to firms or insurance companies that decide not to view genetic testing results of their potential employees/clients.
- How can we ensure that third parties will not take genetic information into account when making decisions, if the genetic information is indeed available to them? Is it perhaps just easier to limit the medical information provided to these third parties as opposed to attempting to control how they use this information?
- Perhaps instead of gaining access to medical histories, laws should only require dire/special medical conditions to be reported directly to third party associations like insurance companies/employers from doctors/individuals, instead of giving such institutions complete access to medical histories.

Bibliography

"About Us | United Nations Educational, Scientific and Cultural Organization." *About Us | United Nations Educational, Scientific and Cultural Organization*. N.p., n.d. Web. 25 June 2013. <http://www.unesco.org/new/en/unesco/about-us/>.

Answers.com. Answers, n.d. Web. 25 June 2013. <http://www.answers.com/topic/genetic-information-ethics-privacy-and-security-issues>.

"Genetic Discrimination." *Genetic Discrimination*. N.p., n.d. Web. 25 June 2013. <http://www.genome.gov/10002077>.

"Genetic Discrimination." *Wikipedia*. Wikimedia Foundation, 25 June 2013. Web. 25 June 2013. <http://en.wikipedia.org/wiki/Genetic_discrimination>.

"Genetic Information." - *Definition from Biology-Online.org*. N.p., n.d. Web. 25 June 2013. <http://www.biology-online.org/dictionary/Genetic_information>.

"Genetic Information." *: Definition of in Oxford Dictionary*. N.p., n.d. Web. 25 June 2013. <http://oxforddictionaries.com/us/definition/american_english/genetic-information>.

"Genetic Information Discrimination." *Genetic Discrimination*. N.p., n.d. Web. 25 June 2013. <http://www.eeoc.gov/laws/types/genetic.cfm>.

"Genetic Information Nondiscrimination Act." *Wikipedia*. Wikimedia Foundation, 25 June 2013. Web. 25 June 2013. <http://en.wikipedia.org/wiki/Genetic_Information_Nondiscrimination_Act>.

"Genetic Testing." *Wikipedia*. Wikimedia Foundation, 25 June 2013. Web. 25 June 2013. <http://en.wikipedia.org/wiki/Genetic_testing>.

"Genetics." *Wikipedia*. Wikimedia Foundation, 25 June 2013. Web. 25 June 2013. <http://en.wikipedia.org/wiki/Genetics>.

"History of Genetics." *Wikipedia*. Wikimedia Foundation, 05 May 2013. Web. 25 June 2013. <http://en.wikipedia.org/wiki/History_of_genetics>.

"The Privacy of Genetic Information." *Bioethics:*. N.p., n.d. Web. 25 June 2013. <http://www.thedoctorwillseeyounow.com/content/bioethics/art1981.html?getPage=1>.

"Refworld | UN Economic and Social Council Resolution 2004/9: Genetic Privacy and Non-discrimination." *Refworld*. N.p., n.d. Web. 25 June 2013. <http://www.refworld.org/docid/46c455a50.html>.

Appendices

I. International Declaration on Human Genetic Data - http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html

II. UN Economic and Social Council Resolution 2004/9: Genetic privacy and non-discrimination - http://www.refworld.org/docid/46c455a50.html